MINNESOTA'S CARE SYSTEM FOR THE DEVELOPMENTALLY DISABLED:

"Developing a system based on need"

POSITION PAPER

AFSCME Council 6 11-19-84 The care system for developmentally disabled people in Minnesota consisted for many years of large state residential hospitals. The past ten years have seen great changes in that system due to the impact of several forces. Social pressure to make the lives of retarded people as normal as possible and to reintegrate retarded people into the larger community has brought about a proliferation of community-based services. Day programs, sheltered workshops, and residential facilities have come into existence in response to that pressure for normalization and deinstitutionalization. But development has been incomplete and inadequate. The result is a policy vacuum, a multiple non-system with little coordination or integration of the many services that now exist.

Federal legislation and judicial action within Minnesota and elsewhere have magnified this pressure by encouraging a move to community-based residential facilities for 15 or fewer residents. Changes in Medicaid policy add to the pressure for smaller facilities without providing for the full range of services that have been available in the state hospital system.

This policy vacuum affects residents of the state hospitals and their families, who see their range of choices of care being whittled away. The lack of a continuum of care and services to developmentally disabled people outside of the hospital system, and the lack of coordination in the services that do exist, are a cause of anxiety even when normalization is the goal.

Minnesota is also losing fiscal and quality control as private, for-profit business corporations move into the present policy vacuum. Some fine attempts have been made at the state level to maintain fiscal control, but increasing privatization and the accompanying lack of coordination make fiscal control more and more tenuous. Quality control also becomes difficult as an already over-burdened county social service system attempts to meet the demands imposed by proliferating for-profit residences and the lack of support services in counties throughout the state.

In addition to the impact on clients and the social service system, deinstitutionalization threatens state hospital employees and the communities in which they live. Thousands of people who are committed to and trained in the care of developmentally disabled people fear that their lives and their communities will be completely disrupted if the state hospitals are simply shut down with no provision made to reduce that disruption.

AFSCME takes the position that neither perpetuating the state hospital system as now constituted, nor eliminating hospitals entirely, will be the best policy for Minnesota in the long run. The best policy is to develop a systematic, state-wide program of care for developmentally disabled people. Such a system will include hospitals, state-owned and operated intermediate facilities and smaller group homes and semi-independent living situations, as well as privately owned and operated facilities. Such a state-initiated, state-monitored program will retrieve fiscal control at the state level, control which is absent in the present agencies and foster homes. A creative solution to fiscal and social problems is needed, a vision for the future that will give long-term stability and ensure quality of care for Minnesota's developmentally disabled people.

The problems in the present non-system are many and varied:

- 1) Private, for-profit facilities have "skimmed" clients, either by refusing to serve all but the easiest clients, or by rigidly specializing so that residents are segregated according to their disabilities.
- 2) The public dollars spent on care delivery go to profits rather than to improving care. In some private residences, training and experience in caring for developmentally disabled people count against prospective employees. Training is not uniformly available and often is not encouraged by owners. Staffing is often minimal and turnover is high, due to the push to increase profits. More subtly, the way the work is viewed changes when profits, not the best care, is the goal.
- 3) Monitoring and evaluation of care become increasingly difficult as privatization develops. Access to facilities and systematic procedures to address problems are far less likely when care delivery is private.

- 4) Continuity, so important to developmentally disabled people, becomes problemmatic when business corporations control care delivery. The problems Minnesota has seen with the privatization of nursing homes and health care delivery are examples of what we can expect with increasing privatization of services for retarded people.
- 5) Decentralization and normalization, the goals and motivation of change, have not happened. Private facilities for large numbers of residents are no less institutions than state hospitals. Ghettoization also occurred, with most of the private residences located in urban areas, and concentrated in a few neighborhoods within those urban areas.
- 6) Consistency of care throughout the state cannot exist without coherent policy at the state level.

What Minnesota needs is a care system for developmentally disabled people that is uniform and coherent, a system which will include smaller facilities where that is of benefit to residents. At the same time, such a system must not waste present state investments in staff and buildings. This is particularly true when those investments can be used wisely to provide a cost effective, coordinated care delivery system.

AFSCME proposes that Minnesota develop such a system on a state-wide level, using present hospitals as regional hubs for a full continuum of services. The regional networks will include the present hospitals, gradually reorganized as resource centers and residences, state-owned and operated community residences, private community residences, Day Activity Centers, and other day programs and services. Present hospitals can provide: long-term care for some residents; screening, evaluation and program development; coordination of placement into community facilities; regional coordination of specialized equipment, staff expertise and training; and overall monitoring and evaluation for the system as a whole.

In such a system, clients and their families will be assured of quality care and continuity, as well as access to and clear-cut mechanisms for addressing problems. The state will be able to maintain fiscal and quality control, and be assured of consistency of programs and training on a state-wide basis. Counties

will benefit by the increased residential and day program options offered by the state.

In addition, the economic health of hospital communities will not be jeopardized. Staff will be assured of a gradual transition and the present investment in staff will not be lost to the state.

Minnesota can foster regional economic development, rather than creating structural unemployment in hospital communities. Buildings, services, and equipment can be used to provide services so desperately needed, such as respite care, crisis intervention, and training and program options.

Minnesota has an opportunity to develop a care system for our developmentally disabled citizens that is progressive, thoughtful, and that maintains fiscal and quality control. We can maintain and develop assets in bricks and mortar, and assets in people who are well-trained and committed to working in a care system for developmentally disabled people. All of these goals can be met by developing a state-initiated and state-operated regional system of circles of care for developmentally disabled people in Minnesota.